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ABSTRACT

This report is based on a site visit to a private, for-profit agency that provides community support services to people with severe disabilities in six counties in Minnesota. The organization supports 25 families in its in-home program and 35 people in supportive and semi-independent living services. Services offered include minor physical adaptations to the home, respite care, training and/or assistance in daily living skills, communication, socialization, recreation, consultation on day placement, physical and occupational therapy, psychological and psychiatric evaluation and consultation, nursing and medical services, and behavior management services. The report examines the organization's structure and personnel, outlines the service delivery process, offers descriptions of some of the organization's clients and homes, and notes some problems being faced by the organization. (JDD)

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INDIVIDUALIZED FAMILY SUPPORTS AND COMMUNITY LIVING FOR ADULTS: A CASE STUDY OF A FOR-PROFIT AGENCY IN MINNESOTA

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Individualized Family Supports and Community Living for Adults: A Case Study of A For-Profit Agency in Minnesota

1988

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INTRODUCTION

As we sat talking in her car, Judy, an administrator of this for-profit organization, described her perspective on the difference between for-profit and non-profit organizations.

> The difference has to do with control. Non-profits are run by a Board of Directors and by people all with their set agenda who are charged with guiding the agency administration ....(This company) is built on my philosophy and other people I believe in. Ownership is based on the beliefs, the values I choose. We own it....If I have to put in so many hours to make it work, I do. God bless all my staff too... We manage better because we provide the best services available in our product - services for people with mental retardation...I also want to contribute to society. For all our hours, we can make more at Honeywell or TARGET...If we make it (money) at the expense of our residents then that is evil not if it is because it is a good service and it is dynamic...As an owner, I have not seen a dime, but I expect to. Getting there is part of the challenge.

Judy's description touches on many aspects important to this organization - quality services, control and ownership, challenge, hard work, profit, staff support, and commitment to success. This report examines this organization, its structure and services, its strengths and its dilemmas, including those raised when for-profit companies provide community services and supports for people with developmental disabilities.

BACKGROUND INFORMATION

Background on the Agency

This report is based on a site visit in August 1987 to a private, for-profit agency that provides community services in six counties in Minnesota. The company (as all the staff refer to the organization) was incorporated in 1985, partially in response to Minnesota's home and community-based Medicaid waiver. As of August 1987, the organization supported 25 families in their in-home program and 35 people in supportive and semi-independent living services.

The entrepreneurs who started this agency also operate ten intermediate care facilities for seventy-two people with mental retardation (ICFs-MR) through another incorporated for-profit organization. The owners had worked in large facilities with over one hundred people living in each; they started this company in 1977 because they had a vision of group homes of six to eight people.

These same owners also operate about seven other businesses that sell furniture and household furnishings, manage property, and provide electrical services.

Background on the Site Visit

The purpose of this site visit was not to conduct an evaluation of the program, but to identify and document promising practices in supporting people with severe disabilities in the community and to obtain information regarding issues in providing more individualized services and supports in the community.

This site visit focused only on the agency providing in-home, supportive and semi-independent living services. Information for this case study was obtained through semi-structured interviews with agency administrators, program staff, people with disabilities and family members, visits to the homes of seven individuals and families, and review of a range of state and agency documents.

The Minnesota Context

Minnesota has made extensive use of intermediate care facilities for community homes for people with mental retardation; it has one of the highest number of out-of-home placements in these facilities in the nation (Department of Human Services, 1987). Based on a report (Office of the Legislative Auditor, 1983) expressing great concern with the number of people in these facilities, the Minnesota legislature called for a moratorium on the development of ICFs-MR and directed the Department of Human Services to apply for a home and community-based Medicaid waiver (Minnesota Department of Human Services, 1987).

As of July 1984, Minnesota obtained a Title XIX Medicaid waiver to support people to remain in or return to their homes, or if necessary, to live in "out-of-home, normalized, community settings" (Department of Human Services, 1987). As defined by the state, services offered under this waiver include casemanagement, respite care, homemaker, residential habilitation (i.e., in-home family support services, supportive living services for children, supportive living services for adults), and day habilitation (including supported employment), and adaptive aids.

"The waiver is administered on the state level by the Mental Retardation Division, Long-Term Care Management Division and Health Care Program Division within the Department of Human Services. On a local level, there are 87 counties, each responsible for determining income and service eligibility of clients, assuring program development and monitoring, providing casemanagement and contracting for services." (Department of Human Services, 1987) Counties often contract with private non-profit or for-profit agencies, such as this company, to provide services under the waiver.

In addition, Minnesota also has a semi-independent living state and county grant program and a family subsidy program. Minnesota's deinstitutionalization lawsuit, Welsch vs Gardebring, continues to have a major impact in the state.

THE COMPANY AND ITS SERVICES

The Structure and Personnel of the Company

Unlike non-profit agencies, this organization's decisions are controlled by the owners instead of a Board of Directors. These two men were described by one staff member as "visionaries and individualists who like to be on the cutting edge." An administrator and developer of in-home and supportive living services also describes herself as a co-owner of the company.

The company has approximately 125 staff, mostly part-time workers. Employees can be hired as administrative, program or support services staff. The majority of employees are hired on a temporary basis on contracts for individual people or families. All

program staff have at least one year experience in the field of developmental disabilities, as required under the state's Medicaid waiver.

The management team consists of staff from this company and the one operating the intermediate care facilities. Program directors each work with seven to nine "clients" and may supervise 20-30, mostly part-time staff. Program coordinators, a new management level, have recently been added because of the organization's rapid growth in services. The agency also expanded their professional staff to include a half-time training coordinator and service contracts with behavioral analysts.

Each employee receives an initial orientation in normalization, agency philosophy and individualized services. The second phase of the orientation is specific to the home and the individual with a disability. In the in-home program, parents and/or other staff members may conduct this orientation. Each new employee also spends time individually working with an experienced staff member. Additional training takes place during the first three months. Each year full-time and part-time staff must complete a minimum of 18 hours of inservice training. There are monthly inservices, regular meetings and periodic opportunities to brainstorm with other "residential" staff members.

Obtaining Services: The Process

According to this agency, a family or individual who is interested in obtaining services requests these through the county social worker. The county caseManager determines if the person is

eligible and decides which agency will provide the support services. The casemanager, in conjunction with an interdisciplinary team, decides about the living situation, and the type and number of hours of service. In the in-home program, this agency also meets individually with each family. The agency then submits a cost proposal to the county and the county approves it or not. Cost proposals are developed on an annual basis but can be renegotiated during the course of the year.

For the in-home program, the contract the agency negotiates with the county annually is specific for each family. The guidelines are $64.00 per day per family, but this amount can be averaged over all the families in the county. In addition, there is money available for minor physical adaptations, with guidelines of about $3400/year. For supportive living services the average amount for a child is approximately $11,000/year and for an adult $13,500/year.

Family Support Services: Keeping the Family Together

This agency supports families to keep their children at home through an in-home program funded by the Medicaid waiver. As one staff member said, "Keeping the family together is one of the best things that you can do." Or as a program coordinator stressed "children belong at home with their families." This organization is part of a growing national movement that recognizes the importance of supporting the family to care for their child with a disability at home (Agosta & Bradley, 1986, Taylor, Racino, Knoll & Lutfiyya, 1987).

While many family support programs are designed so families

need to fit the programs, there are aspects of this agency's approach to family supports that enable them to respond more individually and flexibly to each family.

The first aspect of the family support services promoting an individual as opposed to a standard response for each family is the availability of an array of supportive services. In many family support programs, families must choose from one or two options, whether or not those options meet their needs. This in-home program offers families a wide range of different support services. These services are funded under the categories of minor physical adaptations to the home, respite care, training and/or assistance in daily living skills, communication, socialization, recreation, consultation on day placement, physical and occupational therapy, psychological/psychiatric evaluation and consultation, nursing and medical services, and behavior management services. There is also some flexibility within the service categories.

Second, there is an individual family services plan for each family. While some family support service programs have an array of services available, these services are not necessarily planned with and tailored for an individual family. In this program, each family can select from the array the services that make sense for them. The family and agency then work to insure that the services are provided at a time and in a way that is convenient for the family.

> Terri, a small thirteen year old with a beaming smile and sparkling blue eyes lives in a trailer with her mother and stepfather. The family recently moved here from a nearby

county. The family support program will pay for a lift so Terri can get in and out of the trailer in her wheelchair. The agency is locating a new physical therapist who lives closer to Terri's new home. The physical therapist will help Terri's parents do exercises to keep her limber. When Terri is not in school, Jamie, an employee of the agency, spends the day with Terri until her mother returns from work. Jamie helps Terri eat and dress, plays games like Connect Four, goes out with her in the car, and teaches her new things. One weekend each month Terri goes to the home of Lisa, another staff member.

In contrast, Kathy and her family have a different array of services tailored to their specific situation.

Kathy is a very energetic and outgoing 17 year old who moved home after two years in a residential treatment center. She is an avid fan of professional wrestling, feels cooking is one of her strong points, loves dances and dreams of traveling. For the first six months, Jill, an agency employee came to Kathy's home each morning. The morning routine of bedwetting, showering, and just getting going for the day was a difficult time for Kathy, her parents and her sister and brother who still live at home. Now she has developed a routine that is comfortable for both herself and her family. Jill continues to come to Kathy's home, 20-30 hours a week, typically four hours a day on Monday, Tuesday,

Wednesday and Thursday. She also spends four hours on two Saturdays or 8 hours every other Saturday depending upon what Kathy and she will be doing that weekend. Kathy learned to ride the bus to school and the grocery store. Now she is excited about learning to go to her grandparents' house. Sometimes Jill will help her with homework. Kathy sees a psychologist who helped her make a relaxation tape.

Third, this agency recognizes that supports to families need to be flexible to meet their ever changing needs and life circumstances. As one program coordinator said, "Families change so drastically in a short period of time." Terri and her family needed a lift for their trailer because they moved to a new home. Kathy and her family no longer needed or wanted a morning staff person once Kathy developed a workable routine.

As another example of flexibility, one father supported through this program has custody of his nine year old son labelled as profoundly retarded; the son's mother has custody of the other two children. The father has up to 32 hours a week of service he can use whenever he wants. He runs a bar and generally uses it to be at work. The father has two different support people whom he calls directly. They work out f exible hours to meet all of their needs.

Fourth, individualization and flexibility are also reflected to a degree in the funding mechanisms. The cost of in-home family support services can vary markedly from family to family. For example, the range for seven of the families supported by this organization was from $6,000 per year to $25,000 per year. This is a

critical factor in developing support services for families. Not all families are the same and the supports, including the cost of those supports, will vary from family to family. The in-home supports under the state's Medicaid waiver allows for an average cost across families as opposed to a set amount for each family.

Selected Issues in Family Support

With the availability of services and supports for families, many new issues are beginning to arise in this agency and in other places across the country. Key staff at this company recognize family supports, while filling a tremendous need, can also be very intrusive for families. As one staff member said:

> Family dynamics are or can be really difficult. The number of people going into the home can be very intrusive. This family has many staff and if the family doesn't like the staff it can create problems. I had one staff who wanted it their way. I told them it is somebody else's home. You can't do it your way. I tell the staff you do what the parents say if it is legal. Parents have the first say. It is their child.

This agency became conscious of the importance of parent decisionmaking and the intrusiveness of services into family life when they tried to implement rigorous behavioral programs within the homes. "The parents stopped doing it....It is so intrusive to families... Families can be very creative in saying no." To the

agency's credit, they recognized they not the families needed to change.

While these family support services have many good aspects, this organization still is struggling with a number of critical issues. First, while they recognize the importance of natural supports, they are unsure how services can encourage and build on these supports not supplant them. Second, the agency has a strong professional image and the struggle between professional judgment and parent empowerment still remains. Third, family support services are provided in isolation from a philosophy of permanency planning for children (Taylor & Lakin, 1988). Fourth, the agency emphasizes support to the child more than a clear emphasis on the family as a whole. Fifth, these family supports are funded under the Medicaid waiver with the limitations in flexibility and parent empowerment inherent in this funding mechanism. These are difficult issues in family support services, not unique to this one organization or to the state of Minnesota.

Supportive Living Services: The Promise and the Practice

Under the state's home and community-based Medicaid waiver, supportive living services can be provided to adults in their own homes as well as in adult foster homes and in group living situations of six or fewer people. Instead of requiring that a person live in a certain type of facility to receive a certain level of support (e.g., in an intermediate care facility), an adult can receive intense support services and still reside in his or her own home. This is one significant aspect of Minnesota's home and

community-based Medicaid waiver and is representative of a growing trend in this country to support people in homes as opposed to facilities.

In Hennepin County, the county Minneapolis is in, people do own or lease their own places. The other counties this agency works in have only used the waiver to support people in adult foster homes (i.e., the home of another) and in agency-owned or leased homes. This agency does not recognize the significance of home ownership and control (Racino, 1988) and has not pushed the counties to pursue home ownership by people with disabilities. In this organization, complying with bureaucratic issues (e.g., ICF-MR regulations) appears to carry the same weight and importance as some innovative practices such as home ownership.

Since supportive living services are not tied to a facility, people can have more choice in where they will live. As one of the workers said:

> We help people decide in what neighborhood they will live and look for a place that seems right for the people.

This opportunity for people to have a choice about where they live is a major positive step in the area of community living for people with severe disabilities. Todd, for example, chose one place because it was within walking distance to work and school. He could also have a cat which was important to him.

Expediency can outweigh promise in the selection of places. As one staff member described "Tim moved into a townhouse because it

was available. The clients before him were disruptive to neighbors. It would have been hard for anyone to move in there. He tried. He would shovel neighbor's walks and things." The worker recognized the tremendous disadvantage this location placed on Tim.

An array of individually tailored services can be provided under the broad service category of supportive living services. These services can include helping people to become involved in their communities and neighborhoods, additional consultation and support for difficult situations and/or behaviors, assistance in recreation and leisure at home and in the community, menu planning, budgeting and personal finances, individual counseling, learning how to use public transportation, development of individual routines, health and safety, home maintenance, and using community resources. Nursing, psychological, personal care, occupational therapy, physical therapy, communication consultation, behavior consultation, and related services are also available. The type and intensity of each person's services can vary.

Ted's Apartment: Supportive Living and An Adolescent Boy

Ted lives in a townhouse in an upper middle class suburban area development outside Minneapolis. The ranch style house, similar to others on the circular drive, differs only in its green color with light brown trim, the flowers near the mailbox and the large tree in the frontyard.

A nice looking 16 year old, about 6'1", muscular

with sandy blond hair, Ted is a person who enjoys drama and loves weightlifting and wrestling. The people who work with him describe Ted as a caring and thoughtful person. As one staff member said "Ted is a more difficult person to serve, but there are more moments when it is all worth it...He's a caring person." For example, Ted was a tremendous comfort to one of the staff when her dad died. Ted has made lasagna for the neighbors and is the kind of person who comes into a store to let you know your car headlights are on. People enjoy being with him.

Ted purportedly comes from a family where he was abused as a young child. Staff report that he also has a history of aggression and sexual activity with minors and that it is a big deal to simply keep him out of jail. He now lives with a live in staff Sara and receives additional support from Cliff who works in the evenings and a third person who comes on the weekends. The staff also receive consultation from behavior analysts.

Ted has made a lot of changes in his life. One time, while visiting a relative, he ended up alone with a young girl. The next time he was going to visit the relative, he said he was afraid he would be left alone again with the girl. He said it made him nervous. One person who knows Ted said "for Ted to be able to say that was just like a miracle."

Ted developed some good relationships with staff members that seem important in his life. The supports are also

arranged around Ted. When Ted and some of his support staff did not get along, they left, not Ted. Staff members also seem to support Ted's relationship with his mother. Because Ted was going home the weekend I visited, one of the staff members changed his work schedule around. As he said "We try to work around what Ted wants to do. So he can go home this weekend, my schedule needs to change."

Selected Issues in Supportive Living Services

Ted, an adolescent, receives supportive living services in a townhouse. While such an arrangement makes sense for an adult, as a teenager, Ted might still benefit from family living. While better than living in a large group home, this living arrangement may not provide the continuity of homelife and lasting adult relationships that are so critical in the development of youth. This is a complex issue and requires a great deal more attention than it appears to receive in this organization.

Supporting adolescents is also a relatively new experience for this organization; they are just beginning to examine the differences in supporting teenagers as opposed to adults. As one staff member pointed out, Ted has many more responsibilities than most teenagers around the home. Ted also has limited opportunities to spend time outside the home with typical age peers.

Big Lake: A Small Group Home

The House

We arrived in Big Lake, a town in Sherburne County, about

twenty miles outside of Minneapolis. We stopped in front of a large, two story wood framed house, the brown paint peeling from the side. Half the lawn was recently mowed with the back section at least six inches deep. Brightly colored flowers lined the front and right of the house.

The woman who answered the door was Jalaine, one of the staff members. Within seconds three other people joined us. My immediate reaction was this is a group home. In people's own homes, they typically invite you in and go with you to a room where they entertain. Somehow in most group homes that's not what happens. As it turned out David, one of the men who lived there, took me upstairs to look at some things in his bedroom. His room was painted a bright blue but was otherwise quite barren except for two magazines lying on the carpet next to the bed. He showed me a ribbon he received in track at the Special Olympics and his huge closet that held a couple of pants and shirts.

We walked back downstairs. The living room and dining room were homier; the couch and chair look new. On the walls are a several velvet pictures and a computer printout picture of the three men who live in the home. We sit down at the small diningroom table, facing a corner china cabinet used for storage; a small child's record player shows through the glass. An exercycle is off to one side. Another staff member tells me "there is always a money crunch. We want improvements inside the house but the landlord is very slow in doing things. We hired a person from the group home to do the lawn. We get

what we need but no luxuries."

The Men

David is a young man in his twenties with a broad smile and sparkling blue eyes. He seems to enjoy people. According to Wade, one of the staff, David is quite a soccer player. Recently when the workshop closed for three weeks, he went to the library for the first time, to the Wisconsin Dells, fishing to Big Lake and hiking. Wade said he really enjoyed it. David used to go home and see his dad until he died. He sees a couple of men from the nearby group home when they come over for dinner. David purportedly comes from an abusive family background. "It's also hard for him to change tasks. He's used to physical force and abruptness. He just doesn't know the rules." David screams a lot - a peak of 39 times in one day - loud, piercing screams, filled with obscenities. His screaming now seems to be decreasing. They are working on a choice board so that he can have greater control over his environment.

Rod is a 48 year old man who has spent most of his life in institutions. He has lived in state hospitals and in group homes and purportedly has lots of "behavior problems." Rod is a very social person and reaches out for people to be with him. He enjoys listening to his record player. He loves to sit and talk with staff. He also loves polka bands. Rod is not as much an outdoors person as the other two men, but as one person described him "he is fearless." Since he moved in, Rod now has use of two hearing aids for the first time in his life. They

have also ordered him a sound communication system called the WOLFF.

Hank is a tall, nice looking young man in his twenties. He moved from a facility in another county that the state closed over quality issues - 77 residents in an old hotel. Prior to that he lived with his father. His 1985 speech evaluation says he has no speech, but Wade says he both speaks and does some sign. Hank purportedly used to bang his head at the last facility; they have never seen him do that here. "He loves swimming and fishing. He likes the outdoors. His artwork is phenomenal. He can compose a picture independently without cuing. He does geometrical designs." Hank also enjoys watering the flowers along the side of the house and hums a very lovely song.

Small Size Facility: One Critical Issue in Supportive Living

I asked one of the staff members how this home in Big Lake, funded under supportive living services, was different than a group home. She responded:

> .....more one to one than group homes. We are more able to go out in smaller groups to do activities. Three handicapped adults are the most we have in one facility. Some handicapped adults prefer to live alone.

The small size of the home seems to be very important for the quality of the lives of the people living there. The staff

described many opportunities for people to participate in home and community life in a meaningful way. With these increased opportunities for participation, the men in the home seem to have more opportunities for learning. The staff and people with disabilities seem to know each other as individuals. With the size of homes limited to six under the home and community based Medicaid waiver, Minnesota joins a growing national trend toward smaller homes.

While size is a very important issue, this home is based on the same approach to services for people with disabilities that is common to group homes of six, eight or ten people. As the staff member explained, the difference between this home and a larger group home is primarily one of size. For example:

* People seemed to be grouped on the basis of similarity in need or disability instead of on the basis of commonality of interest or desire to live together. All three people have difficulty with speech and have some challenging behaviors. It is also apparently hard for David to live with Rod; it is not likely that they would choose each other as housemates.

* People did not have a choice where they wanted to live and the choice seemed to be based more on the agency's needs as opposed to the preferences and needs of the individuals.

* Although in theory, the funding is tied to the individual people, in practice, this is a house for three people with a budget for three people.

* The agency leases the house, pays the rent and is reimbursed by the county. The house belongs to the staff not the people who

live there. This ownership extends to other aspects of the house, such as answering the door.

* The staffing is based on the needs of the house as a whole as opposed to the individual people. There is shift staffing. One staff member works 2-10 pm on Sundays to Thursday, another from 4-9 pm on Monday to Thursday and four hours on Saturday and a third person sleeps over.

* The routines of the house are determined by staff not by the people who live there. For example, the staff decide when and how often people will eat out.

* The staff talk about the place as a facility and as congregate living. As one person said "we are respectful of client needs as much as you can be in congregate living." The place is not considered first and foremost as people's home.

* The people in the home are clients first (i.e., participants in the program).

What is striking is not that this is a small group home, but that a more individualized approach is possible under the existing funding mechanism. Structural mechanisms (e.g., funding) can encourage more individualization, but in itself are insufficient. The major change that is needed continues to be how we think about people with disabilities and about our shared visions for people's futures. As one staff member said,

> It can be done. It is usually not done. It is a problem in thinking.

We have become wedded to developing group homes and supported apartments. The hardest part will be to change our own way of thinking from group homes to homes and from quality lives for people with disabilities to quality lives. This is a challenge that faces not only this agency, but human service agencies across the country.

Semi-Independent Living Services

This agency also provides semi-independent living services, less than daily support, to a small number of people through state-county funding. Semi-independent living services can vary from a few hours a week to approximately 20 hours/week, depending on the person and the particular county. According to one staff member, it is possible for a person who needs less support to remain in the same home they lived in when funded by the Medicaid waiver. The same staff can also remain; however, the funding source and individual program plans, especially in areas such as recreation and safety would change. The semi-independent living program is about two years old.

Generally, semi-independent living services are available only to people who are considered more capable. The agency has found, however, that people who have a mild disability and are considered aggressive in group homes and people who resent the intrusiveness of staff in their lives, sometimes do better living in their own place.

Luke: Alone in His Place

Luke lives in a small efficiency apartment in a two

story brick building that houses about 15 other apartments. The bed and the small black and white television on a metal stand are the only furniture in the combined bedroom/ living room. There is a small kitchen and a bathroom off the main room. The apartment seems almost barren, except for the curtains, a poster, and the piles of clothes and paper on the floor.

As one of the staff describes him, "Luke is like everyone's younger brother." At 19, he has a wonderful smile, striking blue eyes and a mischievous charm. He just found a job at Taco Belle and blushes when told he knows a young girl who works there. Luke enjoys talking about sports, but isn't playing any now. He knows the St. Paul area quite well. He just went to a water festival on the Mississippi and was shocked I didn't know the Mississippi River started in Minnesota. He watches the news and is pretty up-to-date on current events. He seems to have a wonderful sense of humor and a strong relationship with his primary worker. She invited him over to watch the Vikings game on Sunday.

He wishes he had more money and transportation to get out and about. Walking home at night in his neighborhood is not very safe. Other than staff and his dad, he has few people to share the activities he loves. Luke needs support with some areas like cooking and laundry. One day a staff member said she came in and he was trying to eat uncooked noodles. She said part of what they helped Luke do is to get through the school year. At one point the school recommended

that he be placed in a treatment center. They were able to help him avert that crisis. Now Luke is in jeopardy again. He has been retested and his I.Q. exceeds the cut off for services. Funding for Luke may be terminated.

Selected Issues with Semi-Independent Living Services

Luke's situation highlights some of the issues that are common in the lives of people supported through semi-independent living services both in this agency and in many parts of the country. First, without a strong focus on supporting people to develop relationships with other people, people with disabilities can remain in many ways isolated and lonely. Second, one of the primary issues that people with disabilities often face is that they remain poor; poverty, not disability, can often be of greater concern. Third, people with mild disabilities, including a person such as Luke who has received special education services all his life, often are faced with the prospect of crossing an arbitrary eligibility line that will result in the denial of services or supports that they need in order to live a quality life.

KEY PRACTICES: BEYOND SERVICES

The Importance of Relationships/Commitment

One of the key strengths in this organization is the relationship between the agency employees and families and individuals with disabilities. As one dad mentioned:

> I like Jane. She's a super, super lady.
> I give her a hard time. She takes it, takes it, then gives it right back to me. That's what I like. I stayed with the agency because of Jane. I could get waivered services elsewhere. We couldn't replace Jane.

This same theme was echoed over and over throughout the visit. For example, one of the staff said:

> the biggest difference for Kathy was she had someone committed to her. Cliff (one of the staff) would help her figure things out; (it was) important that Kathy learned she had some skills and (that he) consoled her.

In this agency, the stress on relationships starts with the initial selection of support workers. Families and/or adults with disabilities have an opportunity to meet potential support workers and decide if this is a good match for them. A temporary contract allows time for both the families (or the person with a disability) and the new employee to decide if this is a match that will work. Although all support staff are employees of or on contract with the company, the support workers are hired to work with specific families or individuals; their job description is tailored to their specific work with the family or the individual. The agency recognizes that relationships are key. They often look for people who already have a good rapport with the person and/or their family to be workers. As several staff members mentioned, the technical

skills needed can easily be taught.

In all homes there were examples of good relationships between the staff and the people who live there.

> Ted and Cliff, one of the staff members, have a close relationship. They enjoy doing a lot of things together. Cliff recounted what happened the last time he and Ted went fishing. "Ted stepped on my fishing pole and broke it. I told Ted I was mad but I wasn't going to scream and punch holes in the wall. It was an accident. Ted and I had a good talk after that." Ted says he knows Cliff thinks he is a fine young man. In meeting them, there does seem to be a deep respect and understanding between them.

Other people who work with Ted also have developed a strong relationship with him and enjoy his company. One of the program coordinators said <u>one of Ted's staff</u> had insulted him in front of her. Although this happened months ago, she is still outraged at the situation:

> To embarrass him in front of others, it's terrible... I am glad I now have staff who have a greater respect for people.

In the home in Big Lake the relationships between staff and the people who live in the home also seem warm, caring and full of life. One of the staff, for example, excitedly told me about their fishing

trip, involving two of the men through gestures in the conversation. At one point, the staff member rushed into the other room and came back with a picture of the men at a local bait shop saying:

> I tried to explain to the guys how to bait and reel; I thought it'd never work. Once they were out doing it, the guys figured it out right away...I just couldn't believe that people would pay you to go out and enjoy things like this. (with astonishment in his voice)

The experience seemed to be not simply a community outing or activity, but a memory of a shared event.

In this organization, a good staff person is defined partly by her or his ability to develop a good relationship with the people in the homes. One staff member, for example, has a reputation for working well with people with challenging behaviors. Her supervisor explained:

> Bev is so new at it she doesn't have bad habits. Her philosophy of life fits right in...a firm, but soft-hearted person. She works at those relationships...She is a great storyteller. The clients love it. There is one upmanship with the stories.

Staff members also described other staff members based on the quality of their relationships with people in the homes. Cliff, for example, is viewed as good staff because of his great respect for

the people he works with. Wade is described as a natural, a person who enjoyed being with and doing things with people. Part of the strength of this agency is its ability to promote within the organization the importance of these relationships in the lives of people with disabilities.

While the agency has placed a lot of energy in supporting relationships between staff and the people they work with, there has been relatively little emphasis on friendships, nonpaid relationships with typical people in the community. This is an area they hope to address more in the future. In addition, as described later on, the relationships while good ones, are still characterized primarily by staff-client roles.

KEY PRACTICES: STAFF SUPPORT

Staff Support

This agency is extremely conscious of the importance of supporting staff, particularly in working in scattered sites in the community. As one administrator said:

> Support is simple. Pay more money to hire a high caliber person. You train them and then give them adequate support and supervision...It is critical that there are people who can provide support to staff. They need on-site support..a person they can call and will come.

Staff can also propose extra on-site support if they need it. For example, one of Kathy's staff may want a trained on-call person

to be available since Kathy needs support at some times when the current support staff is not easily available. Unlike some organizations where decisions are imposed on the staff who best know the people, decisions here are often made in conjunction with the staff working in the home and the family and the individuals with disabilities. Behavior analysts work in the homes, with the families, and with the staff sorting out solutions together.

Staff members appreciated the support they received from their supervisors and from each other:

> I just know I like the work and am happy here. It is important to me to have the support of other staff and I get that here.

> Judy is a good support to me. She's a real networker and does a real good job of pointing me in the right direction. She's very committed to what we are doing.

This theme of commitment seemed to be an important aspect of staff members' pride in their work and in the organization. Staff felt that their commitment was shared by many in the organization.

> Commitment is important to me. Sure we would like to go home at five, but if there are things that come up we stay until eight. We do that. We feel it is important. There is a lot of commitment in this agency.

The staff generally seem to enjoy their work and to believe that what they are doing is both meaningful to people with disabilities and to their own lives:

> My job is to enable a person to experience the same quality of life as I do, the same kind of expectations, a feeling of belonging, a network system. For right now, I know I am doing what I am supposed to be doing. I'm still challenged like a Sherlock Holmes' novel. It is fun putting the pieces together.

> I like it. It is certainly a challenge. It is different in the community than in a facility. You need to be more creative to have things work. Waivered services have made a big difference in people's lives.

> It's not work to me. I've been doing this, working with youth, for a long time. This is what I do best. I try to bring out people's potential whatever it is. I'm big on self-esteem. I think people know when they have done well or not. You don't need to keep telling them.

The image of the agency and its role in the human service system also seems to be one of the key factors that motivate and support staff. The internal image of the organization is one of being a client advocate and an organization committed to quality and excellence. As one staff member said:

> The agency is client-centered, a client advocate. We don't give up on people. We serve people other people won't serve. We focus on attaining independence with dignity, a general quality of life.

This theme of fighting on behalf of people, with the counties, the school systems, or other agencies, to obtain services to which the person is entitled, was a theme that often arose. As one staff member concludes: "I am glad that I work for an agency that is willing to take a stand."

ADDITIONAL ISSUES

Perspectives on Community Integration

People in this agency defined community integration in different ways. All agreed, however, that community integration was very difficult to accomplish when people lived in large groups. As one staff member explained:

> What makes it work is the normalcy of it all. If we can get them out in the community doing the same thing that you and I do, that's what makes a difference. That can't be as easily accomplished in group homes and certainly not in an institution.

One person explained that community integration also means different things to each individual. It may mean going out in the community,

taking a risk with something that the person has never done before, or even just partially participating in an activity such as a course. As one staff member said,

> it means taking advantage of things in the community that everyone else does.

When this staff member first started working in human services, she would call recreation places first and let them know that someone with a disability was coming.

> Now I just take it for granted that people have a right to participate in those activities.

Community integration, however, was also described by another staff member as a training program for people with disabilities. While the staff were aware of the need for community participation in activities, the goals of community membership and relationships, and staff members' roles in supporting these to occur have not been examined.

Perspectives on Disability

Several of the staff, who had extensive experience in working with people with multiple disabilities, provided an interesting perspective on supporting people with disabilities in the community. They observed that:

As people become more capable and lead more typical lives, the issues become more complex. In some ways, issues with people with severe disabilities are more straightforward.

I've realized that they are very complex people..much greater than written on paper. There are very complex issues in the lives of people who are the easiest to serve.

These are important observations on the part of the staff members because they can challenge the way in which we think about people with severe disabilities. First, in this field we often talk about people with the most complex needs as if we have a common measure of complexity and as if complexity equated with disability. By continuing to focus on the disabilities of people as the key factors that we need to examine in supporting people in the community, we perpetuate the myth that the primary problem in supporting people in the community is their disability.

Second, life itself is complex. As people with disabilities have more opportunities to participate in community life, choices and options increase. No longer can outcomes in the person's life be neatly controlled by the service system. The more we appreciate the lives of people with disabilities as opposed to programs or narrow aspects of their lives, the more we may see the multiple paths that people, including people with severe disabilities, can take with their lives.

Third, as the staff members said the more we understand people as individuals, the less people look like the disability caricatures

contained in their records.

Clienthood

One of the primary reasons for moving to more individualized supports is for people with disabilities to be able to live ordinary lives in ordinary homes with the supports that they need. People that receive services from this company, however, remain first and foremost clients. This is reflected in the language of many of the descriptions and quotations contained throughout this case study.

This emphasis on clienthood may increase even further as the size of the agency continues to increase. For instance, the addition of an echelon of middle management staff may further increase the distance between the staff and the people supported by the company. While there are many factors outside of the organization's control that contribute to clienthood, many factors can be changed within the agency.

The Continuum of Care

The agency still ascribes to a continuum of care philosophy viewing community living in terms of graduations and movement to less restrictive environments. When the waiver started, according to one agency administrator "our personal agency policy became we will move our residents out into less restrictive environments and have state hospital folks move in. In 1985, 25% of the population rolled over." Staff members spoke of people graduating from the group home to supported living services and about people being too capable for group homes. Supportive living services has apparently

become the next step on the community continuum (see Taylor, et. al, 1987, Taylor, 1988).

Tied in with the emphasis on the continuum is the theme of success in the community. The agency and staff are committed to have people succeed. While this is a laudable goal, there are several major problems with this approach. Success appears to be defined as being on one's own as opposed to interdependence. Instead of people with disabilities having a right to live in the community, the focus is on the person proving they can make it (Taylor, 1987). It is critical that the agency begins to examine this issue.

A For-Profit Agency

The opening of this case study gives one of the administrator's descriptions of this organization as a for-profit agency. This organization is, like all good organizations, built upon a foundation of values. However, the values are profit, quality services, control and ownership, hard work, staff support, challenge and commitment to success. There are many dilemmas that derive from these values when applied to supporting people with disabilities in the community.

First, a primary issue is that the commitment is first and foremost to the development of a quality product (i.e., services for people with mental retardation) not to the people themselves. With our increased understanding of the importance of natural supports and of personal commitment in the lives of people with disabilities, what are the implications of organizations who are committed to the development of services (no matter how good those services may be)?

Second, we are seeing the growth across the United States of many for-profit organizations who are "franchising" their services for people with disabilities. While this organization has apparently avoided many of the potential pitfalls, the emphasis on achieving efficiency (as opposed to supporting quality lives for people with disabilities) is a major part of the current management focus.

Third, the most important type of ownership is ownership and control by people with disabilities and their families, not by organizations. It is critical that this core value of organizational control and its effect on the actual empowerment of families and people with disabilities be examined.

CONCLUSION

This case study highlights how a variety of practices - both good and poor - combine in one for-profit agency that is committed to the development of quality services. While emphasizing the positive aspects of the company, the case study also examines some of organization's struggles and critical issues. The case study is presented in an effort to assist others in improving the ways in which people with severe disabilities are supported in the community and the quality of their lives.

We extend our thanks to the organization, to the individual staff, and to the families and people with disabilities who opened their homes so that we all could learn.

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